



Providing a supportive and informative environment for people with a variety of lung conditions and their carers.

Newsletter May 2011

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Next Meeting

Thursday 12 May
10.30am – 12 noon

The Weston Club,
1 Liardet St
Weston

In this meeting, we will be talking about our conditions and the variety of treatments we use. We want to pool our knowledge about the non-prescribed treatments as well as the prescribed ones.

Inaugural Education Day

On Thursday 14 April, we held the first Education Day organised by The Lung Foundation and the Canberra Lung Life Support Group – particularly by Caroline who organised the venue at the Southern Cross Club, Woden and was very active in spreading the word about the Day. About 70 people heard three excellent talks, both interesting and informative, interspersed with lunch. We thank Juliet and Jenny from The Lung Foundation for their organisation and hope to continue the event annually. Below are summaries of the talks – thanks to Chris Moyle.

The program commenced with a welcome and news from Juliet Brown of **The Australian Lung Foundation (ALF)**. Juliet talked about about some of ALF's actions:

- a brochure on "Getting Started on Home Oxygen" - \$8
- a nurse, Ainsley Ringma, who is available to discuss lung problems on Thursday and Friday. Phone 1800 654 301 (free call). Ainsley has 30 years of nursing experience.
- The COPD Patient Task Force which meets monthly by teleconference. There are ten representatives Australia wide and they are looking for an additional representative from the ACT - either a patient or a carer.
- Stories from COPD patients - on website.
- Lungs in Action: New program at University of Canberra on Tuesdays at 9.30 am with fitness instructor Dr Kate Pumpa - Ph. 6201-2136.
- Pulmonary Fibrosis. A register is being set up to determine how many people have this condition - in the hope this will enable understanding and support for this disease.

Fitness to Fly Derek Figurski

The first speaker was Derek Figurski, Laboratory Manager, Department of Respiratory and Sleep Medicine at The Canberra Hospital who spoke about what people with lung disease should consider before flying.

Blood oxygen levels decrease with altitude, a concern for lung disease patients, whose oxygen levels are already low. Cabin pressure varies, and is a balance of passenger safety and comfort versus operating costs. The percentage of oxygen in the air at sea level is 21%; 15% at 8,000 feet and 17% on a long haul flight. The lowest oxygen levels occur at the end of a long flight and can make people feel unwell, with dizziness and headaches. Oxygen level on shorter domestic flights is 15% and there is low risk of blood oxygen desaturation.

When you get up and walk around on a plane, in a low oxygen environment, oxygen levels drop even further. At 8,000 feet you could have less than 85% oxygen saturation, which would mean intervention in a hospital. The aim is to keep oxygen levels above 85% in flight. A lack of oxygen on board results in shortness of breath, light-headedness, sleepiness and post-flight exacerbations. Patients should not fly during exacerbations or flare-ups.

Strict guidelines have been developed around the world and altitude simulation tests (AST) are available to assess patients' flight risks. ASTs measure heart rate and pulse oximetry while breathing in 15% oxygen levels. The test helps the doctor write a prescription for in-flight oxygen. The doctor also considers previous travel history, recent exacerbations, altitude at place of destination and medical support in arrival country. It could be very helpful to have a stop-over for recovery rather than a tiring longer trip.

Medical clearance to fly is required 5-7 days before travel. Oxygen on plane is at your own expense, and you need to know how many cylinders you need. Airlines have different travel clearance forms to fill out and their policies can be checked out on-line.

Look at the seating plan and don't sit too far from amenities. You might desaturate just by walking 20 metres. Take your own nasal prongs. Carry all documentation and use wheelchairs to get on flight if necessary. Additional stop-overs have benefits. Remember to plan early. It can take months to see a respiratory physician to arrange an altitude simulation test. Finally, know that the risks of flying (especially with good preparation) are quite low, so enjoy your trip!

Is It COPD or Asthma, or Both?

Dr John Nicholls, Respiratory Physician, the second speaker, discussed the difference between these diseases .

Lung problems are common and they are also under-diagnosed. Approximately one third of the population have never reported symptoms to their GP and a lot of people have never heard of COPD. Some people think breathlessness is part of the ageing process, and cut back activities accordingly. Many people are at risk of lung disease because of factors such as smoking and air pollution so it is an ongoing problem.

Asthma	COPD
<p>Asthma is marked by inflamed airways - red and sore airways which cause them to go into spasm. The airways are "twitchy" and patients are prone to episodes of wheeze, chest tightness, dry cough or breathlessness.</p> <p>Asthma can cause chronic and fixed airflow limitations.</p>	<p>COPD patients have more fixed and predictable levels of breathlessness. It can consist of some bronchitis, asthma and emphysema.</p> <p>Chronic bronchitis means mucous is coughed up regularly - on most days.</p> <p>It causes chronic and fixed airflow limitations.</p>
<p>Triggers for episodes of asthma include cold air, exercise, smoke, pollution, allergies and infection. The cause of asthma is unknown.</p>	<p>COPD is a known smoking-related disease. COPD is preventable if smoking and pollution are avoided. COPD can consist of some bronchitis, asthma and emphysema. Chronic bronchitis means mucous is coughed up regularly - on most days.</p>
<p>Asthmatics can achieve normal lung function.</p>	<p>COPD has progressive symptoms such as inflamed and blocked airways and damaged air sacs. Normal lung function can never be achieved.</p>
<p>Generally responds well to bronchodilators such as Ventolin, Bricanyl etc</p>	<p>COPD treatment involves avoiding smoke and pollution, vaccination against influenza and pneumonia, treating flare-ups early, maintaining activity and healthy eating and taking medications as prescribed.</p>
<p>Asthma-related deaths are dropping. In the late-80s asthma deaths peaked and there has been a big improvement in recent years.</p>	<p>COPD deaths, however, are climbing, especially in women, who have caught up with men.</p>

Asthma-related deaths are dropping. In the late-80s asthma deaths peaked and there has been a big improvement in recent years. COPD deaths, however, are climbing, especially in women, who have caught up with men.

Diagnosis of these diseases is by spirometry and chest x-rays. Trust your doctors and ask questions. Pulmonary rehabilitation aims to maintain an individual's optimal physiological, psychological, social and vocational status. Its goals are to control and alleviate symptoms; improve activity tolerance; promote self-reliance and independence; decrease the need for acute resources and improve quality of life. Increasing exercise capacity by 50 metres reduces hospital admissions and breathlessness. Supervised training gives greater improvements than unsupervised training.

Early diagnosis and treatment is the key with these diseases.

Obstructive Sleep Apnoea (OSA)

Dr Carol Huang, Staff Specialist in Respiratory and Sleep Medicine at The Canberra Hospital explained the diagnoses and treatment options for Obstructive Sleep Apnoea.

Obstructive Sleep Apnoea (OSA) is as common as diabetes. During sleep all the muscles relax and the airway becomes a little narrower. With OSA there is repetitive obstruction of the upper airway causing cessation of breathing (apnoea) for short periods. Very little air flows into the lungs and the oxygen level starts to drop. At a certain level the brain wakes the person up and they gasp and take in a big breath of air. This occurs many times during sleep.

There is probably a genetic factor causing this disease and anatomy plays a big role eg the oropharynx narrowing at back of throat, enlarged tonsils and increased neck circumference causing narrowing of the airway. Obesity is an important risk factor in both snoring and sleep apnoea. Sleeping on your back may increase the probability of upper airway collapse.

Symptoms of OSA include excessive daytime sleepiness, loud snoring, nocturnal gasping, choking, witnessed apnoea, weight gain/obesity, unrefreshing sleep, irritability, mood changes, loss of libido and (the most worrying) sleepiness while driving.

A hospital-based sleep study can be performed to assess the OSA with sensors attached to different parts of the body to assess the sleep pattern. A sleep study can also take place at home using a device to record the sleep. This is the preferred option as it is closer to a normal night's sleep.

From the data collected the number of reduced sleep episodes per hour of sleep can be determined. After assessment a CPAP machine may be recommended for use while sleeping. The CPAP was first made in Sydney and has been around for over 25 years. It is basically an air pump to deliver a certain pressure, which increases the airway volume. It works as a pneumatic splint. CPAPs now come in all shapes and sizes.

The CPAP can have side effects such as nasal congestion, oronasal dryness, skin abrasions/rash, sinus discomfort, dry throat, runny nose, chest discomfort, claustrophobia, difficulty exhaling, noise, partner intolerance and inconvenience. These problems often get better. The machine used to operate at 90 decibels, but now operates at 23 decibels. It is quieter than a computer.

There are also oral appliances such as the tongue retaining device which prevents the relaxed tongue from falling backwards and blocking the airway. It fits around teeth and can be uncomfortable. There is also a mandibular splint - a mouthguard to make the tongue come forward. A dentist makes this splint. These devices are only recommended for mild to moderate sleep apnoea, and you need first to buy before you can try. They could bring on jaw pain and are not as effective as the CPAP.

Surgery improves, but rarely cures, moderate to severe OSA.

The Canberra Hospital has a sleep physician consultation service which needs a referral from GP to specialist, plus in-patient and out-patient services and is able to perform sleep studies.

Informative digest of latest lung disease information from Maureen Bell

Medline Plus, a free service of the US National Library of Medicine and National Institutes of Health, offers an email service which you can subscribe to.

To subscribe, Google "**Medline Plus**".

Once you have this website, go to "**About Medline Plus**" (blue box on right) to the section "Want to Learn More?" and click on "Sign up for Email Updates".

I get the **Daily Digest Bulletin** and then either follow or ignore the links provided. You choose which health conditions you want to sign up for so the bulletin doesn't arrive in your InBox on a daily basis, only when there is something new. And of course you can unsubscribe at any time.

Chronic Care Expo

The Chronic Care Expo **Living a Healthy Life – See, Feel, Touch, Do** - is being held on May 14th at Southern Cross Club, Woden, between 10am and 3pm. Your chance to look at ideas for self management techniques in all sorts of areas.

Seniors' Expo

We set up the good looking table in the photo at the Seniors Expo in March in the Kingston Markets Venue along with many others community and professional groups. Always good to see the variety of organisations represented.

Laurelle, Barry and Caroline did the hard work of setting the table up. Other members came later to help: Helen, Chris, Pam, Pat, Maddie. This year, we were able to hand out the pens with our logo on them and the new flyers and we had a reasonable flow of people stopping to talk to us.

It really seems a worthwhile day to participate in and has been well managed in the past few years by Laurelle. Unfortunately, Laurelle is retiring from organising expos and we would like a member to volunteer to take her place. She will tell you it's not an onerous job. Caroline has also played a significant role in the expos and can assist the new organiser.

Many thanks to Laurelle for all the effort and time she has put in over the years. It's been really worth it for our group.



Laurelle and Barry at the Seniors' Expo, Kingston, March 2011

ACT Health Chronic Disease Telephone Coaching Service

A new telephone-based support service is available to ACT residents with chronic disease. The service is tailored to patients with specific conditions including heart failure, coronary artery disease, chronic obstructive pulmonary disease or Type 2 Diabetes.

People enrolled in the program will receive regular phone calls from a registered nurse to discuss their condition and work towards achieving their personal health goals. The coaching is an invaluable tool in helping patients manage their medical care, as well as developing and maintaining a healthy lifestyle.

Referrals can be made by GPs, specialists, medical officers, senior nursing staff (including practice nurses) and allied health professionals. You can send referrals to ACT Health Community Health Intake by phone (02) 6207 9907 or fax (02) 6205 2611.

For a practice visit, please contact Dawn Coulson from Medibank Health Solutions on 0416 175 244 or dawn.coulson@medibank.com.au .

For more information visit <http://www.health.act.gov.au/telephonecoaching>

You will find a flyer for the service at the end of this newsletter

Transmitting pictures by email *from Albert Richards*

There is an interesting little free program called 'Image Resizer' that can be downloaded from Microsoft but only works for Windows XP. It gives you the option of sending attached emailed pictures in a small format that comfortably fits within the screen.

As I expect you are aware large email attached pictures cannot be comfortably viewed without downloading them. The two Websites hereunder explain all.

<http://www.microsoft.com/windowsxp/downloads/powertoys/xppowertoys.msp>

http://email.about.com/od/netiquettetips/qt/et_resize_image.htm

Lungs in Action

A new exercise class for people with lung conditions has begun in Belconnen. Kate Pumpa has set up a 'pulmonary maintenance' class to begin on Tuesday 19th of April at 9:30 am at the University of Canberra in Building 3, room B36.

Participants must have attended acute pulmonary rehab in the last 12 months, or have a medical certificate from their Doctor/specialist indicating they are fit for gentle exercise. The cost will be \$5 per class.

Kate can give you a map of the campus so you know where the building is. There is disabled parking right out the front of the building and both a ramp and lift that will allow easy access to level B (the second floor).

If you are interested, please contact Kate:

Kate Pumpa, Department of Sports Studies, University of Canberra ACT 2601

ph: 61 (0)2 6201 2936; fax: 61 (0)2 6201 5615; email: Kate.Pumpa@canberra.edu.au

ACT Report for ALF COPD Patient Taskforce Teleconference

4 April 2011 by Caroline Scowcroft

Caroline is the ACT representative on the Australian Lung Foundation's COPD Task Force which teleconferences regularly. Here is the report she gave in the last teleconference.

There has been a lot of activity in the time between school returning and the start of inclement weather. The Canberra Lung Life Support Group had stalls advertising the CLLSG, the ALF and various smaller groups such as ASH (Action on Smoking and Health) and the Donate Life campaign - at the Calvary Hospital Open Day and the Seniors Expo held during Seniors Week – both were very successful with many inquiries and networking to help people in the right direction for more support and help in their self-management of chronic conditions. We find these occasions very useful for 'working the room' to strengthen networking opportunities.

A small group of our members were able to attend a University of Canberra training session for Physiotherapy students – we attend 2 of these each year and have been doing so for several years. Members continue to volunteer as patients for medical students and also volunteer for appropriate clinical trials.

I gave a session about volunteering and the power of networking, using the ALF as an example, at a 2-day

training program for new consumer representatives for ACT Health. I also attended a consultation forum on the Draft of the new ACT Primary Health Care Strategy - in these situations, as a health care consumer, we always have the consumer as the primary focus and stress the need for care in the community, for patients and carers, as well as care in the acute hospital setting. I attended a half-day inter-generational forum to discuss themes of ageing in the 21st century – I always manage to get ALF/CLLSG material on display tables (and of course always appear in a green T-shirt – it's a great way to engage people in conversation about 'What is COPD?').

There is a new Lungs in Action program starting at the University of Canberra and the CLLSG has been active in recruiting participants. There is a new Telephone Counselling service for those with chronic conditions – including COPD, several of us are giving it a 'trial' – more when we have some results. We are looking forward to the Inaugural LungNet Education Day, so far the arrangements are going smoothly and we have a good number coming.

Caresearch: www.caresearch.com.au

Caresearch is a website dealing with palliative care, giving information on options and aiding decision making. CarersACT is holding a one hour session on how to use Caresearch. It will be held on Wednesday, 14 May, 11am to 12noon at CarersACT, 2/80 Beaurepair Cres, Holt.

You need to register by phoning Eleanor on 6296 9908 or emailing: eleanork@carersact.asn.au

Consumer Representative Training

Health Care Consumers (HCCA) are holding FREE training sessions so you can become an effective consumer representative. When? Saturday 28 May and Saturday 4 June from 10am-3pm.

Where? At their offices, 100 Maitland St, Hackett, 2602. To register, phone: 6230 7800 or email: heathermcgowan@hcca.org.au

Ready & Able – *Keep your brain active* by Chris

Here's the answers to last month's Mix and Match.

- | | |
|-------------------|-------------------|
| 1. John WAYNE | 5. John TRAVOLTA |
| 2. George PEPPARD | 6. George CLOONEY |
| 3. George LAZENBY | 7. John MALKOVICH |
| 4. John GIELGUD | 8. John CLEESE |

The _____ surgeon was _____ to operate as he had _____.
Unscramble the following letters to make a word which fits into the first space. Then, keeping the letters in the same order, split the word to make two words, which fit into the next two spaces. Finally, split the word again to make the last two words.

B T E N L O A

Answers next month.

Dates for your diary

Wednesday 18 May Chronic Conditions Self Management Expo – Southern Cross Club, Woden

Wednesday 16 Nov World COPD Day



Chronic Disease Telephone Coaching Service



How does the program work?

This service is provided by registered nurses and includes:

- Regular support calls at a time that is suitable to the patient
- An individualised plan to help patients achieve their personal health goals over one or two years
- Appropriate support and information relevant to their health condition
- Assistance in accessing local community services
- Advice on effective communication with health professionals
- Provided free of charge to ACT residents

Who is this program for?

People diagnosed with:

- Chronic heart failure
- Coronary artery disease
- Chronic obstructive pulmonary disease
- Type 2 diabetes



How to access the service

Referrals can be made by GPs, specialists, medical officers, senior nursing staff and allied health professionals. Contact ACT Health's Community Health Intake line on:

☎ (02) 6207 9977

☎ (02) 6205 2611

✉ CHI, GPO Box 825, Canberra ACT 2601

Further information can be obtained by contacting the Chronic Disease Management Unit of ACT Health on (02) 6207 6833.

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